**GENERAL DATA PROTECTION REGULATION - PRIVACY NOTICE FOR RESEARCH PARTICIPANTS**

As you may be aware the General Data Protection Regulation (GDPR) came into force on 25 May 2018. We are committed to the GDPR’s data protection principles and have updated our Privacy Notice.

We know how important it is for you to understand how we use your data. This statement sets out why we collect, store, process and share your personal data. More information is available on our websites: <http://www.prion.ucl.ac.uk/welcome/> and <http://www.prion.ucl.ac.uk/clinic-services/>

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research.  This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Your rights to access, change or move your information may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from a study, we may ask if we can keep the information about you that we have already obtained but it will be up to you to decide. However, it will be difficult to retract data that has been processed and anonymised.

To safeguard your rights, we will use the minimum personally-identifiable information possible in our research. Research data is often shared with our collaborators in the UK and internationally - such data will have personal identifiable information removed. We take a robust approach to protecting personal data - ensuring access is strictly controlled and limited to authorised individuals. UCL has information security policies and procedures in place to ensure data is kept safe and secure. Personal data and associated information will not be kept for longer than necessary. The length of time for which we keep your data will depend on a number of factors including the importance of the data, funding requirements and UCL’s Records Retention policy.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/).

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO). Our Data Protection Officer & Freedom of Information Officer can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).